Witness Name: GRO-B
Statement No: WITN7436001
Exhibits: 0
Dated: December 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. I reside at GRO-B GRO-B My date of birth is GRO-B I am divorced and live with my eldest daughter who is still at home, she is in her early 20s, I have another daughter at university in Georgia in America, which is where her dad lives. My husband and I separated whilst I was taking part in a HepC drug trial and I have been a single parent for the last 12 years. I continue to pay an excessive amount for mortgage protection (due to HepC), and although being 63 I will need to continue to work until I am 70 to pay off my mortgage.

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement. I have made a request for my medical records.

Section 2. How infected

3. I had surgery to remove my gallbladder and as a result needed a blood transfusion after (or possibly during) the surgery. I have a vague memory of starting to wake up feeling unwell, and saying I was going to be sick, and I can remember the medical team talking about me needing blood, but then don't remember any more. Afterwards I was informed that the surgery was not as straightforward as expected and I had lost a lot of blood which was why I had been given a blood transfusion. The blood came from Kingston Hospital, Kingston-upon-Thames, Surrey. This was the first surgery I had ever had. I was previously always in excellent health and had only needed to visit my GP for gynaecological issues. As I was given the transfusion as part of the surgery, the risks etc were not discussed with me.

4. This surgery was the only way I could have contracted Hepatitis C. I lead a very healthy lifestyle and had no other risk factors.

5. I thought no more of it and then around a year later I went to give a blood donation, I wanted to pay back as it were and that's when I found out about Hepatitis C. I had had no symptoms up to this point and was completely unaware I had contracted the virus until they tested my blood. The NHS contacted me to say I had Hepatitis C antibodies and I was not allowed to give blood. I had donated blood several years earlier which was accepted without question.

6. Even once I found out I had the virus I had no actual symptoms from it for at least 2 or 3 years before my levels were changing enough to discuss any kind of treatment with me.

7. I was given no information about the risks of blood transfusions as it was given in an emergency situation and I had not properly come round to be able to discuss it.

8. When the NHS contacted me to inform me of the infection, they stressed very clearly that I didn't have HIV.

9. From what I remember, I think I got a letter telling me about the antibodies and telling me not to panic that it was not HIV and I believe I may have gone to the GP and was then referred to Kings College Hospital for them to manage it, I would go for regular check ups and had regular liver biopsies. At the time I lived in Surrey and had to take a day off of work to attend these appointments. I think I went every 6 months to begin with, the infection had no real effect on me for a number of years. I have a letter dated October 2004 from Dr Philip Harrison a Senior Consultant Hepatologist to my GP following a recent check-up, wherein he confirmed that my only risk factor was the blood transfusion and my liver tests had remained normal and had done so for the last 2 years. Biopsies in 1996 and 2001 both showed mild disease and he said that I was not a candidate for treatment at that stage as the side effects were worse than the disease. I had a repeat biopsy in 2006 and that altered things and I then became a candidate for a drug trial.

10. With hindsight, I think that because I had no symptoms myself, I didn't really think that much about it, it was not particularly affecting me. I had been told to declare on any insurance forms that I had been tested and that I had HepC, so I just sort of lived with it at that point. I did feel constantly tired generally it became my normal and I just accepted it. When I was first diagnosed, I did not get much information at all about it, probably because I didn't have symptoms and was recently infected. I didn't question it. It was not until I started the drug trial, then I was given a lot of leaflets with side effects information, and was told to keep a diary of how I felt literally every day, morning and evening. So, while I was on the drug trial I was given tons of information and they checked on me constantly, but prior to that nothing really, they were not very forthcoming as my liver disease was not advanced enough for them, my symptoms were progressing slowly.

11. Looking back I was just in shock really, initially I was just relieved I did not have HIV, I did not know anything about Hepatitis infections at all. I wasn't a person who went to the doctors very much at all, in my last place of work I had 1 day off in 20 years, I probably should have questioned it more, but I didn't and because I didn't ask questions no one else made me more aware.

Section 3. Other Infections

12. I do not believe I have been infected with any other infections other than Hepatitis C, but I cannot be certain of this or the long term affect to my liver done by the disease whilst I had it.

Section 4. Consent

13. I was not treated without my consent or knowledge, whenever Kings took biopsies I was always asked if I was happy for my liver samples to be used to advance cures and I always gave them consent for that.

Section 5. Impact of the Infection

14. Before I started the drug trial I felt stigmatised because I had to make insurance companies etc aware. I didn't really tell anyone at all apart from my family that I had it. At this point I didn't have particularly noticeable symptoms so I didn't really need to tell anyone, it was only when I started on the drug trials that the side effects of these were very evident to everyone, mentally, physically, literally every area of my life was affected by the side effects of the drug trials. Immediately Prior to the drug trial I worked part time. When I was initially infected I had a high-powered job working for a Computer Software Company. I left to have my two daughters and continued to work but on a part-time basis to fit in with family life. Once the drug trial started I was unable to work. I was too unwell and not physically able or presentable.

15. Physically, during the first one, I had to take tablets, you don't lose your hair but it goes incredibly sparse. I would also be very itchy so would be ripping at my legs, they would be covered in scabs where I had been scratching. The sun also affected me, I couldn't go out in the sun much, I had no energy whatsoever, I walked around in a daze. My immune system was wrecked and I caught every cold and virus in circulation along with frequent UTIs. I had a particularly bad bout of Norovirus which left my husband thinking I was about to die. I had to keep a diary, it was like I was on suicide watch with all the diary information, they said my husband had to keep a close eye on me as a side effect was depression and attempted suicide. The first drug trial lasted for a year, and after 6 months of finishing that treatment it had been successful, but year post trial it hadn't which was devastating news for me and my whole family. A few months later I was offered a second drug trial.

16. The second drug trial (which was a double-blind trial) was a combination of tablets and injections into the stomach and again the side effects were awful, I had incredibly terrible mood swings and depression and no energy whatsoever. I looked really ill by this point, the side effects were much worse than the disease itself, but I was prepared to do it in the hope it would get rid of the disease.

17. I also had to declare the infection on everything by this point, I was married with a mortgage and even now as a single person with a mortgage, I am rated 4 or 5 times higher than other individuals for life insurance, which means I am paying 5 times more than I should be and have done so for the past 28 years! I am lumped in with people who got the infection from drug use. As a single person now I am currently paying for mortgage protection of £50 a month for a relatively low mortgage to cover it until I am 70 and I had a real struggle with even getting the mortgage and it affected the rates I could get.

18. I believe the infection and the symptoms caused by the treatments played a huge part in my marriage breaking down. It didn't help the situation that I had terrible mood swings and depression and was unable to work. I was also

concerned about my children catching it from me as I was told then, there was no treatment for children if they caught it, so I was better off not having them tested as they would have to declare they had been tested. To this day they have not been able to give blood or be tested for fear if they did have it there was nothing that could be done.

19. To my knowledge I don't appear to have had further medical complications or conditions that have resulted from the infection to date.

20. I have had no difficulties recently in relation to treatment or dental care. When I had my second daughter I was flagged, so I had a room on my own and everyone had to put gowns, gloves and masks on before they came in to see me so it was very unpleasant, there was just a general stigma so I don't tell anyone even now.

21. I don't know if there were treatments that should have been made available that were not. Originally, I was told that there was no treatment at all, and only with me being prepared to take part in the drug trials has there ended up being a treatment available. I imagine that the second drug trial I took part in might have been the one that ended up with good results and has progressed to being a worthwhile treatment for others, luckily it was successful for me. I had a years' worth of treatment and then came off it for 6 months and had to go back and check that I was still virus free for another year.

22. There was a massive impact on my life as a result of the infection. I wasn't able to have a social life of any kind, I was so lacking in energy, I looked awful, I didn't go anywhere while I was on the drugs trials. Prior to that I was tired, but I was much younger then, even when I tried to go on family holidays I had to get special letters to allow me to take syringes on the plane as I was having to administer injections along with the tablets. I couldn't drink alcohol with the medication, although not that I drink now, I can't, you can't even have social drink so it does impact, my children didn't enjoy my company and my husband definitely didn't. He had to take on much of the day to day child care as well as running a company. Our relationship broke down irretrievably

23. I used to work in a computer software company in customer services, involved in networking and programming which I did not go back to once I had my first daughter in 1998. When having treatment I couldn't work, I didn't work while having the treatment not until it finished and got the results of the treatment which weirdly coincided with around the time my husband left me so it all happened at once. I didn't work because I physically was unable to. After the trial finished I worked part time for my husband as he had an events company so I did a bit of his office work from home but physically would not have been able to do a full-time job.

24. As I hadn't been working, when my husband left, I had to sell up my home and move with my two daughters and get my own mortgage, so I ended up in a very different situation than I had previously been. My ability to get a competitive mortgage and life insurance was hugely impacted by HepC.

25. The infection had a massive impact on my family, it was extremely upsetting for all of them. I lived an hour and a half away from my parents so I didn't see them every week. Friends didn't really comment on how I looked, no one did, they asked how I was but that was it. I hadn't seen my sister for a few weeks on one occasion and she was so upset and shocked when she saw me she literally cried and said 'oh my god look at the state of you, why haven't you told me'. I looked really awful with my hair thinning and looked shocking.

26. There was also an impact on my children, they probably just thought I was very bad tempered and unwell all of the time. Every aspect of their life at that time was affected. I couldn't go on family outings or take them to play with friends or have friends around to play. I didn't tell them what was wrong with me, with most people I tended to say I have got a liver issue that's why I don't drink. My children were under 10 so probably just thought that's the way I was that I was miserable and a bad mother. It all then blew up with their dad, it affected my marriage, the side effects, in particular of doing the year of the drug trial that didn't work and the second drug trial, so really I was not in a good place for around a 4 year period so would have been a lot for him and them to deal with.

Section 6. Treatment/care/support

27. I was not offered any counselling, I arranged my own counselling when I felt I needed it, I had to pay £50 per session, initially I had it weekly but could not afford it so had to change to monthly.

Section 7. Financial Assistance

28. I have had no financial assistance whatsoever. One of the specialist nurses I regularly saw at Kings College Hospital encouraged me to apply to the Skipton Fund, I got the forms and completed them but my GP seemed reluctant to support me because my blood transfusion was in 1994, after the 1991 cut off period. However numerous medical professionals in the Liver Unit at Kings said that the blood transfusion was the only way I could have been infected.

Section 8. Other Issues

29. It has been incredibly difficult to get any information about what support might be available. My current GP (now retired) was not at all helpful when I asked him if he would be prepared to support my application. When I saw specialists at Kings, they made it very clear the only way I could have contracted the infection was from the blood transfusion. I didn't even know about the inquiry or any support really until I saw it on the news, there is not enough publicity or support available for people in my situation. I believe there are a substantial number of us that have been infected after 1991.

30. I had contacted EIBBS and I was informed the 1991 date is still a cut off date but they did not discourage me to apply as they have spoken to others in the same situation and they can't confirm I would not be able to register with them.

Anonymity

1. I wish to remain anonymous.

2. I do want to give oral evidence to the Inquiry.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed................ GRO-B ....

Dated..................21/12/22...